

III. Methods

The needs assessment process used several strategies to gather input. The centerpiece of the process was the creation and distribution of written surveys to persons living with HIV/AIDS (PLWH) throughout King County. Other components of the needs assessment process included a written service provider survey, focus groups of targeted consumer sub-populations and key informant interviews with service providers.

A. Consumer Surveys

The 2001 consumer survey targeted persons living with HIV/AIDS throughout King County. The survey was based on ones developed in previous needs assessment processes. (See Appendix D for a copy of the consumer survey instrument.) The HIV/AIDS Planning Council's Needs Assessment Work Group oversaw the development of the survey instrument, and staff from Public Health – Seattle & King County were responsible for survey distribution, collection and analysis.

The Planning Council sought to collect information on a wide spectrum of persons living with HIV/AIDS in King County, ranging from individuals who were HIV positive but not yet symptomatic to persons with end-stage illness. The process emphasized traditionally underserved populations, including persons who were homeless, were dually or triply diagnosed (with HIV and mental health or substance use histories), women, youth/young adults, persons of color and persons living in South and East King County. Survey forms were created both in English and Spanish language versions.

The survey inquired about 36 types of HIV/AIDS-related services offered in the King County Continuum of Care. Consumers identified each service either as one that they needed and used, did not need, or needed but could not get. For services that were identified as “need, but cannot get,” consumers were asked to identify the reason(s) why this service was unavailable. The survey also asked consumers to choose up to seven of the services that they would consider most important for them.

In response to an increased focus on medical care access by the Health Resources Services Administration (HRSA), the Planning Council added a new component to the 2001 survey. The survey asked consumers to identify the services they felt were most important in helping them access or maintain medical care (“access services”). The survey also collected demographic information, as well as information related to HIV health status and medication adherence issues.

In creating the survey instrument, the Planning Council made extensive efforts to safeguard the anonymity of survey respondents. Survey instructions explicitly stated that consumers should not include their names, addresses or phone numbers on return surveys. To further safeguard respondents' confidentiality, the surveys were pre-addressed to the “Planning Council,” rather

than the “HIV/AIDS Planning Council” or “Public Health – Seattle & King County.” Survey forms were bar coded for pre-paid reply.

To reach as broad a range of consumers as possible, survey distribution sites included 65 service agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed at the offices of 34 private medical care providers and 11 private dentists. Public Health delivered a total of 2,700 surveys to the various agency and provider sites. Based on follow-up inquiries of agencies and providers, between 1,585 and 1,878 surveys were actually distributed to consumers. The Planning Council received a total of 538 valid responses, for a return rate of between 27% and 32%.

Efforts to reach traditionally underserved populations appeared to be successful. Survey demographic data indicate that 14% of respondents were women versus 9% of estimated King County PLWH, 27% of respondents were people of color versus 26% of PLWH estimates, and 12% of respondents identified heterosexual contact as the primary mode of HIV exposure versus 5% of PLWH estimates. The survey also appeared to be effective in reaching South and East King County PLWH, with 20% of respondents listing a non-Seattle zip code, comparable to estimates suggesting that 18% of King County PLWH live outside Seattle.

Additionally, 11% of respondents reported being homeless within the past year, 7% reported having been incarcerated within the past year and 30% of respondents reported having been diagnosed with a mental illness. Each of these percentages represents an increase over those reported by consumers on the 1999 survey.

As in previous years, however, two populations appear to have been under-represented among survey respondents: persons between 20-29 years of age (9% of survey respondents versus 23% of King County PLWH estimates) and heterosexual injection drug users (3% of respondents versus 7% of PLWH). Younger PLWH are less likely to know their serostatus, which may explain the low response rate among this cohort. The low percentage of self-identified injection drug users may represent under-sampling of this population or may indicate that respondents were not willing to disclose histories of substance use on the survey form. If the latter is true, this may correlate with the high percentage of respondents who reported heterosexual contact as their primary mode of transmission (12% of survey respondents versus 5% of PLWH estimates).

B. Provider Surveys

The Planning Council created and distributed a provider survey as another component of the 2001 assessment process. The Council believes that service provider data offers important comparisons to consumer-identified service priorities and gaps, as well as helping to gather input about sub-populations that may not have been effectively represented among consumer survey respondents. (See Appendix E for a copy of the provider survey instrument.)

The survey collected information from as broad a range as possible of providers of service to persons living with HIV/AIDS in King County as possible. These included primary care

providers, case managers, providers of non-Western therapies, private dentists, substance use and mental health treatment professionals and staff from human service agencies throughout King County.

Public Health distributed provider surveys at 59 agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed to 40 private doctors and 11 private dentists.

The survey inquired about the type of service offered by the provider, the total number of persons with HIV/AIDS on the provider's current caseload, and demographic breakdowns related to the provider's HIV/AIDS clientele. Using the same list of 36 HIV/AIDS-related services that appeared on the consumer survey, providers were asked to identify up to seven services that they believed were most important for their client populations. The survey also asked providers to check each service that they felt was needed by a substantial number of their clients, but that clients were having trouble accessing, and to identify the top seven services that the provider believed helped his/her clients to access or maintain medical care.

Public Health delivered a total of 561 surveys to the various provider sites. The Planning Council received a total of 254 valid responses, for a return rate of 45%.

Efforts to reach providers of traditionally underserved populations were very successful. Survey responses indicate that 18% of the overall consumer population served by responding providers were female (versus 9% of estimated King County PLWH) and 29% of the clients served were people of color (versus 26% of PLWH estimates). Additionally, 37% of the providers' clients identified exposures other than male/male sex (versus 30% of PLWH estimates). Providers also reported seeing a higher percentage of youth and young adult PLWH (12% of the survey respondents' caseloads versus 1% of King County PLWH). Additionally, providers reported that an average of 15% of their clients had been homeless within the past year, 11% had been incarcerated within the past year, 46% had a history of chemical dependency and 37% had been diagnosed with a mental illness. These figures also represent increases from percentages reported by providers on the 1999 survey.

C. Consumer Focus Groups

The needs assessment process included eleven focus groups to gather in-depth qualitative information from specific sub-populations of persons living with HIV/AIDS in King County. The questions posed to participants focused on access to medical care (both at time of initial HIV diagnosis and currently), service needs, gaps in services, and overall impressions of the HIV/AIDS care service delivery system in King County. (See Appendix F for a copy of the focus group script.)

Focus groups were held with the following sub-populations of PLWH:

African Americans

Men who have sex with men (MSM)

East King County PLWH
Homeless persons
Injection drug users (non-MSM)
Latinos (conducted in Spanish)
Native Americans

MSM/IDU
South King County PLWH
Women
Youth and young adults

The focus group strategy acknowledges that specific sub-populations of PLWH may present unique utilization patterns, access barriers and service gaps, and addresses the concern that written surveys might not be as well suited to capture information from members of several of the sub-populations. A total of 81 PLWH attended the eleven focus groups.

Based on input from providers of services to Asian/Pacific Islander PLWH, Public Health attempted to conduct one-on-one interviews with members of this population in lieu of a focus group. Providers noted that linguistic differences, as well as client concerns about safe-guarding their anonymity, make recruitment for a focus group extremely difficult. Unfortunately, only two Asian/Pacific Islander PLWH expressed interest in being interviewed. Because it would be difficult to generalize information from these individuals to the population of A/PI PLWH as a whole, the interviews were not conducted. Public Health will work with the Planning Council to explore potential means of gathering more useful data from this population in future assessments. As a result, information regarding service utilization and needs of A/PI PLWH are limited in this report to quantitative data from consumer surveys and key informant interviews of service providers to this population.

Service providers across the Continuum of Care disseminated information about the focus groups within the targeted communities, identified potential participants, and secured appropriate meeting spaces. Provider “hosts” were also invited to attend the focus group to assist in creating a safe environment for the participants. In five of the eleven groups, the providers felt that group members might be more candid without them present, and they chose not to remain after the initial introductions.

Participants received \$20 for their time, as well as reimbursement for transportation and/or child care expenses incurred. Staff recorded each of the groups on audiotape. In addition, a non-participant observer took written notes at each group to assist in the final transcription.

D. Provider Interviews

In order to capture qualitative information about clientele and service trends, staff from Public Health – Seattle & King County interviewed 34 HIV/AIDS care service providers in King County. The providers supplied demographic information about their client population and identified trends or changes that they observed in their clientele. Providers also noted the types of HIV/AIDS-related care services that their clients most frequently utilized, as well as identified access barriers and system gaps in service delivery experienced by their clients. (See Appendix G for a copy of the provider interview form.)

As with the focus groups, providers were identified based on their affiliations with specific sub-populations of PLWH. The interview roster included medical providers with large HIV/AIDS caseloads (representing private, clinic and hospital-based practices in Seattle, East and South King County), case managers, mental health providers, substance use treatment facility staff, and jail health staff. Public Health staff also interviewed service providers at several King County community-based organizations (including organizations targeting women, persons of color, youth/young adults, and homeless persons). Each interview lasted between forty-five and ninety minutes. Although most interviews were conducted with individual providers, some providers were interviewed in pairs.